



Care and support
through terminal illness

Routes to impact: influencing guidelines for people with advanced dementia

People with advanced dementia may experience problems with eating and drinking as they reach the end of life. Common symptoms of this include decreased appetite and swallowing difficulties, and when such problems arise it is sometimes necessary to provide nutrition, hydration and medications directly into the stomach. This is known as enteral feeding.

A common form of tube feeding is known as a percutaneous endoscopic gastrostomy (PEG). This is where a tube is inserted directly into the stomach through the abdomen. It is inserted by invasive surgery, which is sometimes a risk for the patient. Careful deliberations need to take place prior to making decisions about artificial feeding, and pressure to feed a person can come from both professionals and the family and/or carers of the person with dementia, who may often have conflicting thoughts on what would be best for the patient.

In 2009, Marie Curie funded researchers Dr Liz Sampson, Dr Bridget Candy and Dr Louise Jones published a Cochrane review (a way of carrying out research into health-related issues) of enteral feeding in people with advanced dementia, in an attempt to identify what the benefits might be to feeding this way at the end of life¹. The review found that there isn't enough evidence that artificial feeding is beneficial for people with advanced dementia.

The evidence from the review was included in the most recent National Institute for Health and Care Excellence (NICE) guidelines, published in 2018, regarding the assessment, management and support for people living with dementia and their carers². The guidelines now recommend that enteral feeding should not be used routinely for people with advanced dementia. NICE guidelines are used by health and social care professionals to guide practice based on research evidence.

In 2018, with this research in mind, NICE also developed a decision tool to assist people with dementia, their carers and professionals in discussing feeding options towards the end of life³. In this decision aid, NICE suggest that an alternative to enteral feeding can be to offer food and drink that the person likes, or, if unable to swallow, moistening the lips with the food or drink so they can taste it. This idea of 'comfort-only feeding' has been used more commonly in end of life care for people with dementia with the Royal College of Physicians and British Geriatrics Society now recommending 'comfort feeding to minimise risk and increase enjoyment and quality of life in older adults nearing the end of their lives'⁴.

In addition, Alzheimer's Society have also published information on feeding in advanced stages of dementia and refer to the evidence outlined by Dr Sampson and colleagues⁵. Marie Curie's nutrition policy for clinical staff also has information regarding 'comfort-only feeding' as a person nears towards the end of life, if certain criteria are met.

The impact has not been confined to the UK. The American Geriatric Society released a position statement in 2018, reporting that feeding tubes are not recommended for older adults with advanced dementia, suggesting hand feeding for comfort and pleasure is more appropriate⁶. The Cochrane review conducted by Dr Sampson and colleagues is referenced in the rationale for this recommendation.

Decisions around feeding choices can come as a shock to family and carers, however, if discussed with the person and/or their family in advance, they may be able to make plans for what care or support they would like to receive in the future.

The research carried out by Dr Sampson's team has also supported the new NICE guidelines recommendations on advanced care planning due to the confusion surrounding decisions about feeding at the point of need. They recommend that people should be given information about making advanced decisions about medical treatment, and are given regular opportunities to review these. This can include whether that person would like to be fed artificially or not.

This research will have an impact on individuals by preventing undue distress and confusion for people with advanced dementia who may have previously been tube fed. Reducing tube feeding in clinical practice may ultimately have an economic impact by reducing costs to the healthcare system in the long term.

1. Sampson E.L. et al. (2009), Enteral tube feeding for older people with advanced dementia. Cochrane Database of Systematic Reviews (2). pubmed.ncbi.nlm.nih.gov/19370678/
2. National Institute for Health and Care Excellence (2018), Dementia: Assessment, management and support for people living with dementia and their carers, (NICE Guideline 97). Available at: nice.org.uk/guidance/ng97
3. Decision aid: Enteral (tube) feeding for people living with severe dementia, (2018), NICE Guideline 97). Available at: nice.org.uk/guidance/ng97/resources
4. British Geriatrics Society (2012), Dysphagia Management for Older People towards the end of life, Good Practice Guide, British Geriatrics Society. Available at: bgs.org.uk/resources/dysphagia-management-for-older-people
5. Alzheimer's Society (2016), Making decisions and managing difficult situations. Available at: alzheimers.org.uk/get-support/daily-living/making-decisions-artificial-feeding
6. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee, (2014), American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement, Journal of American Geriatrics Society. Available at: onlinelibrary.wiley.com/doi/full/10.1111/jgs.12924

Marie Curie is the largest charitable funder of palliative and end of life care research. The charity invests nearly £3 million each year into research to help inform better quality of care for people with any terminal illness, and the people who care for them.

**For more information contact:
research.info@mariecurie.org.uk**